

...offering
**information &
*inspiration***
to individuals with
disabilities and
their families
as they direct their
own supports and
services



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A 'Real' Celebration

Susan Daniels, Disability Rights Activist to Speak

Families, service providers, and policy makers will come together this fall to celebrate the recent 'systems change' efforts that brought about Real Life Choices.

Billed as a 'first of its kind event,' the celebration will give families and consumers with disabilities the opportunity to meet with government leaders and network with others who are living in the community with Real Life Choices. The event is being hosted by the Division of Developmental Disabilities (DDD), in conjunction with Neighbours, Inc., a Princeton-based not-for-profit agency that provides support services for people using self-directed services.

The keynote speaker is Susan Daniels, a nationally-recognized expert and spokesperson on employment and disability policy. She has over 15 years of experience successfully leading large Federal agencies through policy development, organizational change, and customer service innovation. As Deputy Commissioner for Disability and Income Security Programs at the Social Security Administration for the Clinton Administration, she spearheaded disability and employment reform activities.

Dr. Daniels contracted polio as a child and although she spent much of her young life in rehabilitation institutes and hospitals, her parents strived for her full independence. After attending a mainstream school, she went on to graduate summa cum laude from Marquette University, received a Masters in Psychology from Mississippi State University and earned a Ph.D. from the University of North Carolina.

"We encourage families to attend and join the celebration," said Cherry Oakely, Director of Support Coordination at Neighbours, Inc. "This will be a chance to see where we have been, and where we are going with this system's change."

Real Life Choices was established by DDD in 2002 to provide assistance to eligible families so that they can remain together for as long as possible while ensuring that, as their needs change, a residential option is available.

The day-long celebration is free of charge, and will take place at the Westin in Princeton on Saturday, October 21 from 9:00 a.m. - 3:30 p.m. For more information, please call 609-275-0606.

Mark Your Calendar

**Saturday, October 21
9:00 a.m. - 3:30 p.m.
Westin, Princeton**

I Know There is Quality When...

Reflections of a Father on The Meaning of 'Quality'

I know there is quality in my daughter's life when:

- She refuses Saturday lunch with me because she is having lunch with her boyfriend.
- We go for a walk in a local park on a Sunday afternoon and fellow walkers greet her with "Hi Becky."
- One of the women on her inclusive bowling team invites her to a meal at her house.
- She has work and volunteer jobs in the community where she is valued for her contribution.
- She has a boyfriend who makes her laugh and who she makes laugh.
- She has Wilbur, a guinea pig, to care for and love.
- She makes needlepoint and pottery for gifts to family and friends.
- She has money to buy a second TV for her bedroom, take a trip to Cap Cod or Disneyland, and join CURVES.
- Her three sisters agree that Becky lives life far closer to her potential than any one of them.

These are just a few snapshots of Becky's life that give me the clues to know that she leads a quality life.

But what is the single most important source of this quality? It is long-term enduring relationships with individuals without a disability.

Self-determination expert Tom Nerney points out that the single greatest predictor for health and safety risks is the absence of such relationships. I would take that idea further and say positively that the presence of long-term enduring relationships with family, staff, co-workers, and others in the community, not only minimizes risks, but also contributes to higher levels of quality, self esteem, and even self-actualization.

"...being in the community has opened up the opportunity for satisfying higher level needs - belonging, love and self-esteem."

While considering 'Quality of Life' and how we measure it for individuals with or without disabilities, I remembered Maslow's "Hierarchy of Needs."

To refresh your memory, this triangle shaped hierarchy has five levels, starting at the base with physiological needs (sleep, hunger, thirst). Next is the need for Safety and Security, then the need for Belonging and Love. Toward the top, is a higher need for Esteem and the respect of others, and at the top, is the need for what Maslow called 'Self-Actualization,' the pursuit of aesthetic needs and fulfillment.

It occurred to me that the quality indicators in Becky's life were higher up the scale, even reaching to self-actualization.

Fifty years ago, when custodial care in institutions was the norm, people with disabilities were stuck at the bottom. Their physiological and safety needs were met, but little more. Sometimes not even that.

As individuals moved into the community, the tendency was still to focus quality assurance efforts at these two basic levels of need. But being in the community opened up the opportunity for satisfying higher level needs - belonging, love, and self-esteem.

I mentioned that Becky's sisters believe that she comes the closest of the four of them to realizing her full potential. She is approaching self-actualization.

The challenge is to find a way to assure that individuals with disabilities can be supported in realizing these higher levels of human needs. Perhaps this starts at the bottom, but we must include the higher levels of needs in all of our person-centered planning. We must incorporate the resources to realize these needs in our funding, and then find a way to assure that individuals with disabilities have opportunities to fulfill those needs.

by Quincy Abbot , 2004; edited for length. www.self-determination.com

Boggs Center On Developmental Disabilities Announces Fall Lecture Series

As part of the Elizabeth M. Boggs Center on Developmental Disabilities' Lecture Series, nationally-known speakers travel to our state to discuss issues of interest and concern to people with disabilities, their families and those who work on their behalf. The Boggs Center invites professionals, parents, people with disabilities, policy makers and community members to attend any individual lecture, or the entire series.

Northern Series - Woodbridge Hilton, Iselin NJ

October 6 ■ Who Will Care for Our Loved One? Family Caregiving & Planning for the Future

Featuring Tamar Heller, Ph.D., of the University of Illinois, this session will present trends in family support and will provide a model for involving parents, siblings and individuals with disabilities in making plans for the future.

October 20 ■ Sex, Love & Relationships

Featuring David Hinsburger, a consultant from Ontario Canada, this session will focus on teaching people with disabilities about relationships and sexuality. Strategies for assisting individuals in relationship development, and helping parents deal with fears will be addressed.

Southern Series - Doubletree Guest Suites, Mt. Laurel, NJ

October 27 ■ Medicaid Update: Major Recent Federal & State Initiatives Impacting People with Disabilities

Featuring Jeffrey Crowley, M.P.H., of Georgetown University, this session will provide an overview of positive and negative changes to Medicaid from the perspective of people with disabilities, and will emphasize strategies that New Jersey advocates can take.

November 14 ■ Preparing Youth with Disabilities to Successfully Transition to Postsecondary Education & Employment

Featuring David Johnson, Ph.D., of the University of Minnesota, this session will address implications for state and local assessment of accountability systems, challenges in meeting student's academic and transition needs, and access to post-secondary education and employment, in an effort to improve transition programs and services for youth with disabilities.

The programs are offered free of charge, however, registration is required. An admission pass will be sent to confirmed registrants. Lectures begin promptly at 9:30 a.m. and end at 12:30 p.m. For more information, or to register, visit <http://rwjms.umdj.edu/boggscenter>, or call Wendy Kuziemski at 732-235-9325 or e-mail her at wendy.kuziemski@umdj.edu

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Name _____

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Send to:

New Directions
CCS Communications
P.O. Box 384
Hopewell, NJ 08525

or e-mail:

consid@comcast.net

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Editor: Brenda Considine

CCS Communications
P.O. Box 384
Hopewell, NJ 08525

phone/fax: 609-466-0694
consid@comcast.net

New Bill Would Help Ensure Safety of People With Disabilities



U.S. Senators Robert Menendez (D-NJ) and Frank R. Lautenberg (D-NJ) have introduced a bill in the U.S. Congress that would require staff working with individuals with developmental disabilities or traumatic brain injuries to call emergency services in the event of a life-threatening situation. The legislation would raise the standard of care nationwide by improving staff training and ensuring that individuals with developmental disabilities get emergency care when they need it.

The bill is named in memory of 32-year old Danielle Gruskowski of Carteret New Jersey who died when staff members at her group home failed to call 911 following a severe fever and respiratory complications.

"I'm proud to be an advocate for the families in New Jersey who are counting on safe, secure and healthy independent living environments for their loved ones with disabilities," said Senator Menendez.

U.S. Representative Rush Holt, also of New Jersey, has championed the bill in the House of Representatives. A similar measure was passed by the New Jersey Legislature in 2003.

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New Jersey Council on Developmental Disabilities
P.O. Box 700
Trenton, NJ 08625

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